

review title

Personalised risk communication for informed decision making about entering screening programs (Edwards et al 2006)

focus of the review

The aim of this Cochrane review was to assess the effects of different types of personalised risk communication for consumers making decisions about participating in screening programs. Studies included in the review compared 'personalised risk communication' with general risk communication for people/consumers contemplating:

- mammography
- breast cancer screening and genetic testing
- high cholesterol screening
- cervical screening
- colorectal cancer screening
- prostate cancer screening

Personalised risk information includes individualised risk scores or actual risk information (either absolute or relative risk); categorisations of risk based on risk estimates; or discussion of a person's own risk factors relevant to the screening decision.

key results of the review

This review shows that:

- personalised risk communication interventions, compared to general risk communication interventions, may be associated with a small increase in the uptake of screening
- more detailed personalised risk communication interventions may be associated with less of an increase in screening uptake

This review does not show the effects of:

- personalised risk communication interventions on risk perception, intention to take tests, and other cognitive and affective consumer outcomes

this bulletin summarises a Cochrane systematic review

the first part of the bulletin is a summary of the review

the evidence table in the second part contains more detail of the review

this evidence bulletin is provided by the Cochrane Consumers & Communication Review Group

background to the review

Patients are increasingly involved in healthcare decisions and there is growing interest in facilitating genuine consumer involvement and informed decision making. Screening programs now aim to achieve both. In healthcare generally and screening in particular, there is limited understanding about what constitutes adequate communication of risks and benefits to consumers.

Screening programs provide a variety of risk information to stimulate discussion and decision making or to motivate people to attend screening. There is growing awareness that the way risk information is presented may influence consumer decisions about participating in screening. Some programs provide information that is more personally relevant to the consumer and personal risk estimates have been shown to be effective. 'Personalised risk communication' interventions have been incorporated into several healthcare areas including treatment, prevention and screening. However the effectiveness of different strategies has not previously been investigated. More individualised or personalised information for consumers may have a variety of cognitive and affective outcomes including improved knowledge and perception of risk, and decreased anxiety and decisional conflict.

studies included in the review

Twenty two studies were included in the review; they were randomised controlled trials including more than 7,500 participants. Thirteen of the 22 studies focused on a personalised risk communication intervention for mammography screening programmes; four addressed breast cancer risk and genetic testing; three addressed cervical screening; two each addressed high cholesterol screening and colorectal cancer screening; and one addressed prostate cancer screening. Most studies were undertaken in the USA. The interventions were delivered by healthcare professionals ranging from physicians and nurses to staff specifically recruited and trained for the intervention studies.

applicability of included studies

The studies included in this review focus on consumer decisions about screening. Although the studies' interventions primarily aim to have an effect on screening uptake, they also aim to affect elements of informed decision making more broadly (e.g. knowledge and perceived risk).

Interventions in these studies focus on a variety of modes of delivery (e.g. telephone, in-person, print material, computer based). Different types of personalised risk information (e.g. person's own risk factors, tailored text about beliefs) are compared to delivery of general risk information (e.g. information about population or 'average' risk of contracting a disease). Study participants range in ages from 18 to 84 years and include individuals, couples, and parents making decisions on behalf of children. Outcomes primarily relate to health behaviour, communication and knowledge (e.g. screening test uptake, appropriate use of test, accuracy of perceived risk); and other outcomes relate to health status and wellbeing, and health behaviour (e.g. anxiety and intention to take test).

description of interventions, outcomes

Review authors state that screening aims to sort out people who are well who may have a disease from those who do not have a disease. In the review's included studies a variety of personalised risk communication interventions were compared to general risk communication interventions. Personalised risk interventions included:

- individualised risk score or actual personal risk information;
- categorisations of risk status based on estimates for individual (e.g. high, medium or low risk status);
- discussion of a person's own risk factors relevant to the screening decision.

More specifically the included interventions investigated, for example, the effects of:

- a tailored intervention to increase compliance regarding mammography in low income African-American women; 'tailoring' comprised listing of personal risk factors for women whom 'perceived susceptibility';
- tailored risk notification programme for women aged over 30 with a family history of breast cancer (the intervention group people

EVIDENCE BULLETIN

5 SEPTEMBER 2007

summary of
the review
continued

- received a letter listing personal risk factors and a genetic booklet);
- individualised breast cancer counselling, involving a discussion of personal risk factors, presentation of individualised risk estimates in women aged 35 and older with a family history of the disease;
- a computer based strategy aimed at increasing uptake of cervical screening among women; risk factors were summarised in printed format;
- a postal questionnaire appraising the risk of coronary heart disease (CHD) on cholesterol screening uptake (people with answer scores above a certain level were advised to have the cholesterol test);
- a colorectal cancer risk appraisal including a statement of the individual's risk; and
- personalised (tailored) intervention for carpentry workers, who have occupational risk factors for colorectal cancer; risk factors identified from a baseline survey were fed back.

Most studies (14) measured uptake of screening outcomes. Five studies measured changes in risk perception or perceived susceptibility. Five also measured intention to take tests. There were only a few other outcomes with relevant or reliable data. Three studies measured knowledge, and two studies measured anxiety. Individual studies provided data for outcomes such as comprehension and stages of change.

what the review shows: summary of key findings

Small increase in uptake of screening

There is some evidence of a significant effect overall of personalised risk communication interventions (written, spoken or visually presented) on uptake of screening tests compared to general risk communication; the trend is towards a small increase in uptake (14 trials, 7341 participants).

Within the overall trend, more detailed risk communication information (i.e. individualised risk estimates), compared to general risk communication, was associated with less of an increase in screening test uptake.

Increase in knowledge

There is some evidence that personalised risk communication interventions, compared to general risk communication, may increase knowledge (2 trials of 3 showed significant increases).

Appropriate use of cholesterol screening tests

There is some evidence that personalised risk communication interventions (e.g. risk appraisal questionnaire), compared to general risk communication, may lead to appropriate use of screening tests for cholesterol (1 trial, 3152 participants).

Accuracy of risk perception

Three trials showed a trend towards increased accuracy of, or improvement in, risk perception in the personalised risk communication group (3 trials, 1264 participants) although there is insufficient evidence overall to decide between personalised and general risk communication intervention groups.

Other outcomes: insufficient evidence

There is insufficient evidence to decide between personalised and general risk communication in relation to other key outcomes including: perceived risk as a screening candidate, anxiety, intention to take screening test, improvement in risk comprehension or understanding, making recommended behaviour changes, satisfaction with decision, decisional conflict, costs, 'appropriate' uptake, or health status.

what the review does not show

This review does not show the effects of personalised risk communication interventions on risk perception, intention to take tests, and other cognitive and affective consumer outcomes.

conclusions

Review authors state that there is a trend towards more emphasis on informed decision making in the literature, and that this is reflected in the review's included studies; earlier studies in the review focus primarily on screening uptake, while more recent studies are looking at a broader range of outcomes incorporating outcomes such as knowledge and perceived risk.

Authors acknowledge it is difficult for researchers and clinicians to provide personalised communication for consumers and this is evident in the lack of data in the screening area.

EVIDENCE BULLETIN

5 SEPTEMBER 2007

summary of
the review
continued

However this is an emerging field; there is a tension between public health goals and individual choices, and it is necessary to evaluate whether policies of greater patient involvement in decision making mean that patients are actually making more informed or adequately informed choices.

recommendations

Authors recommend that a broader perspective on increasing informed decision making for screening be sought in research and evaluation. To fully address 'informed choice' investigations should include:

cognitive outcomes such as:

- knowledge; and
- risk perception.

affective outcomes such as:

- decisional conflict;

Funding

This Evidence bulletin is provided by The Cochrane Consumers and Communication Review Group (CC&CRG) with funding from the Helen Macpherson Smith Trust and the Department of Human Services, Victoria, Consumer Participation and Information, Quality and Safety Branch. Bulletins in this series are created for the Health Knowledge Network (HKN) and in support of Evaluating effectiveness of participation (EEP) projects.

Monthly bulletins and feedback from members

We will provide monthly bulletins until the middle of 2008—Evidence bulletins will alternate with Resource bulletins.

Forwarding of bulletins is encouraged and we welcome feedback on bulletins' format and content.

- satisfaction with decision making;
- anxiety; and
- making decisions consistent with individual's values and preferences.

Authors state that there would be value in developing a generic means of assessing informed decision making for screening choices by consumers. Such measures must be able to demonstrate informed decision making by consumers, and to demonstrate this requires consensus on what constitutes informed decision making for screening.

Authors additionally recommend that new research examines a broader range of risk communication interventions in a wider range of clinical areas and for a range of diseases.

Bulletins are available on The CC&CRG website , select *Health Knowledge Network* at the website: <http://www.latrobe.edu.au/cochrane>

Contacting us

Cochrane Consumers & Communication Review Group (CC&CRG)
Australian Institute for Primary Care
La Trobe University
VIC 3086

Helen Dilkes, Information Officer

Ph: 03 9479 5730

Fax: 03 9479 5977

h.dilkes@latrobe.edu.au

Cochrane Consumers and
Communication Review Group



Full citation for the review:

Edwards AGK, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database of Systematic Reviews* 2006, Issue 4. Art. No.: CD001865. DOI: 10.1002/14651858.CD001865.pub2

Full text is available in The Cochrane Library at: www.thecochranelibrary.com



EVIDENCE TABLE

This table contains detailed data extracted from the review, and expands on the summary on previous pages of this EVIDENCE bulletin. This table uses standardised wording developed by Dr Rebecca Ryan, Cochrane Consumers & Communication Review Group. A key to this wording follows the table and should be used to interpret the data.

Review title: Personalised risk communication for informed decision making about entering screening programs.

Authors: Edwards AGK, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ.

Description of main features

Aim: To assess the effects of different types of individualised risk communication for consumers making decisions about participation in screening.

Study design:
RCT

Participants:

Included: People facing 'real life' decisions about whether to undergo screening. This may involve individuals making decisions on their own behalf and those making decisions on another's behalf, or couples making decision together. Screening activities must include an investigation performed by a health professional, for example, mammography, colorectal and prostate cancer screening, antenatal and neonatal screening and genetic screening.

Excluded: Studies examining mass communication; those examining military, school or prison based interventions only, where consumers are less free to make a choice. Studies in which individuals face hypothetical decisions were also excluded.

Interventions:

Included: Interventions that include personalised risk information. Personalised risk information includes individualised risk scores or actual risk information (either absolute or relative risk); categorisations of risk based on risk estimates; or discussion of a person's own risk factors relevant to the screening decision. Interventions also include those which address decision-making about screening tests, that is tests aiming to identify an unrecognised disease or defect, and intended to identify apparently well people who may have a disease from those who do not. General risk communication interventions include, in comparison, population risk estimates, general information on risk factors, or general encouragement to acknowledge risks or to alter risk-related behaviours.

Personalised risk information interventions could be delivered before screening, at the time of screening, or at the time of counselling or promotion of screening.

Excluded: Studies investigating only health education or promotion to reduce risk or increase screening adherence without accompanying discussion of risks and benefits of screening. Studies where the main basis of the intervention was generalised rather than personalised communication of risk.

Comparison arms:

Personalised risk communication interventions versus general risk communication interventions.

Outcomes:

Included: cognitive outcomes (risk knowledge, accurate risk perception); affective outcomes (anxiety or emotional well-being, intention to take up screening, decisional conflict, satisfaction with decisions made); behavioural outcomes (test uptake, adherence to screening program choice, appropriate uptake), health status outcomes (specific QoL measures) and economic outcomes.

Number of studies included: 22

Types of studies included: RCT

Number of participants included: >7,500

Meta-analysis performed: Yes.

Review methods: Standard Cochrane Collaboration review methods were used, including the following: *a priori* research design provided; extensive searching including searching for unpublished studies; selection criteria were specified in advance and applied; list of included and excluded studies provided; quality criteria for assessment of included studies were reported and applied; methods of analysis were reported; conflict of interest stated.

Quality:

Included studies: Rated using adapted Jadad scale and the 'Method Score' used in risk communication literature. Quality assessed based on allocation concealment, blinding of outcome assessors and use of intention-to-treat analysis.

Included studies were of variable quality. Overall the standard was good although only 2/22 studies adequately concealed allocation; 7/22 used intention-to-treat analysis; and most were rated as unclear on blinding of outcome assessors.

Review AMSTAR rating (out of possible 11):* 10 - high quality review.

Comments: The review methods adequately met all items of the AMSTAR checklist with the exception of the item evaluating assessment of publication bias: the likelihood of publication bias was not explicitly addressed by the review.

Setting: *Country:* Majority from USA; also Canada (2 studies), and Australia (1). *Intervention:* Variable, included: in-home interview or mailed information/questionnaire.

Recipient: Interventions directed to the consumer.

Provider: Variable: Ranged from physicians and nurses to research staff recruited and trained for the intervention study.

Format: Variable: written, oral, video or electronically presented risk information. Conditions for which tools were used were also variable: over half (13/22) of included studies described interventions in the context of mammography screening; 4 studies addressed breast cancer risk and genetic testing; 3 addressed cervical screening; 2 addressed cholesterol screening; 2 addressed colorectal cancer screening; and 1 addressed prostate cancer screening.

Intervention	Results of review
Personalised risk communication interventions versus general risk communication interventions	<p><u>Primary outcomes:</u></p> <p>Some evidence from trials: of a significant effect overall of personalised risk communication interventions on uptake of screening tests. However, a trend towards a small increase in uptake of screening tests associated with personalised risk communication interventions was observed (14 trials, 7341 participants) (OR random effects model 1.31, 95% CI 0.98, 1.77).</p> <p>Some evidence from trials: Within the overall trend towards an increase in uptake of screening following personalised risk information communication interventions, more detailed risk communication information appeared to be associated with less of an increase in screening test uptake. That is, for interventions containing the most detailed risk information (individualised risk estimates), the OR for test uptake was 0.83 (95% CI 0.65, 1.03), while for categorical risk calculations (high, medium or low risk categories) the OR was 1.42 (95% CI 1.07, 1.88). In comparison, risk communication that simply listed personal risk factors, the OR was 1.42 (95% CI 0.95, 2.12).</p> <p><u>Other outcomes:</u></p> <p>Some evidence from trials: that personalised risk communication interventions may increase knowledge: 2 trials of 3 showed statistically significant increases in knowledge.</p> <p>Some evidence from trials: that personalised risk communication interventions are associated with appropriate use of screening tests for cholesterol (1 trial, 3152 participants) (OR 1.32, 95% CI 1.14, 1.55).</p> <p>Insufficient evidence from trials: to decide between personalised and general risk communication interventions with respect to accuracy of perceived risk, although a trend towards increased accuracy of perceived risk was seen in the personalised risk communication group (3 trials, 1264 participants).</p> <p>Insufficient evidence from trials to decide between personalised and general interventions with respect to other outcomes including perceived risk as a screening candidate (1 trial, 204 participants), anxiety (2 trials, 499 participants), intention to take screening test (5 trials, 2016 participants), improvement in risk comprehension or understanding (1 trial, 200 participants), or making recommended behaviour changes (1 trial, 890 participants).</p> <p>Insufficient evidence in relation to measurement to decide between personalised and general risk information with respect to satisfaction with the decision, decisional conflict, costs, 'appropriate' uptake, or health status.</p> <p><u>Harms/ adverse effects:</u></p> <p>Insufficient evidence in relation to measurement. Authors note the need for more relevant and complete outcome measures of affective variables including anxiety for people undergoing screening decisions.</p>

The table on this page presents the standardised wording that should be used to interpret the data in the results section of the EVIDENCE table on the previous two pages.

SUMMARY STATEMENT	TRANSLATION
<i>Sufficient evidence from trials</i>	<p>Evidence to support conclusions about the effect of the intervention(s) in relation to a specific outcome(s). This includes evidence of an effect in terms of:</p> <ul style="list-style-type: none"> • benefit or • harm. <p>Statistically significant results are considered to represent sufficient evidence to support conclusions, but a judgement of 'sufficient evidence' is also based on the number of trials/ participants included in the analysis for a particular outcome.</p> <p>A grading of 'sufficient evidence' is often based on meta-analysis producing a statistically significant pooled result that is based on a large number of included trials/ participants.</p> <p>This judgement may also be made based on the number of trials and/or trial participants showing a statistically significant result - for example (in a narrative synthesis) a result where 12 studies of a total of 14 for a specific outcome showed a statistically significant effect of an intervention would be considered to represent 'sufficient evidence.'</p>
<i>Some evidence from trials</i>	<p>Less conclusive evidence to make a decision about the effects of a particular intervention(s) in relation to a specific outcome(s).</p> <p>This may be based on narrative syntheses of review results. In this case, the result is qualified according to the findings of the review - for example, 'some evidence (5 studies of 9) reported a positive effect of'</p> <p>{This would be based on a more equivocal set of results than those obtained for 'sufficient evidence' above. For example, while 12/14 statistically significant studies would be classed as 'sufficient evidence', 5/9 statistically significant studies is more equivocal and would be classed as 'some evidence.'}</p> <p>This may also be based on a statistically significant result obtained in a small number of trials; or a statistically significant result obtained from trials with a small number of participants.</p>
<i>Insufficient evidence from trials</i>	<p>Not enough evidence to support conclusions about the effects of the intervention(s) on the basis of the included studies. This should be interpreted as 'no evidence of effect', rather than 'evidence of no effect'.</p> <p>Statistically non-significant results are considered to represent insufficient evidence.</p> <p>Where the number of trials is small, and/or the number of participants included in the trials is small, 'insufficient evidence' might reflect underpowering of the included trials to be able to detect an effect of the intervention.</p> <p>Where the number of trials is large, and/or the number of participants included in these trials is large, 'insufficient evidence' may reflect underlying ineffectiveness of the intervention to affect the outcomes being examined.</p>
<i>Insufficient evidence in relation to measurement</i>	<p>Not enough evidence to support conclusions about the effects of the intervention due to a lack of reporting on the specified outcomes.</p> <p>This can be the result of :</p> <ol style="list-style-type: none"> (i) the review electing not to report on a particular outcome, or set of outcomes, despite being reported by the included trials; or (ii) the review was not able to report on the outcome, as data for the outcome was not reported by the included trials. Note: used for reporting against outcomes only.
<i>N/A</i>	<p>Not applicable to the outcome category of interest. Note: used for reporting against outcomes only.</p>